

FOR IMMEDIATE RELEASE

debra of America Celebrates National Epidermolysis Bullosa Awareness Week with 16th Annual Benefit For Children with Painful Genetic Disorder on October 22 at B.B. King Blues Club

Gamble For A Cure For “Epidermolysis Bullosa (EB) – The Worst Disease You've Never Heard Of.™”

New York, NY (October 7, 2014) — The 16th Annual debra of America Benefit presented by Mölnlycke Health Care will be held Wednesday, October 22 from 7:30PM to 11:00PM at B.B. King Blues Club in New York City. The benefit will honor **James Wetrich** in recognition of his retirement from Mölnlycke Health Care and years of service to the **EB** community. The event marks the beginning of National Epidermolysis Bullosa Awareness Week, which was legislated by Congress in 1984 and occurs annually from October 25 through October 31. **EB Awareness Week (#EBweek)** was created to increase awareness of this rare and painful genetic disorder, to promote the need for a cure, and to spur advocacy initiatives on behalf of those suffering with the emotional, financial, and physical burden of Epidermolysis Bullosa.

The 16th Annual debra of America Benefit will feature casino games for prizes and vacations, sweet and savory bites, complimentary bar, a premiere 100 item silent auction, and a special musical performance. The 2014 Co-Chairs are **Alan Kalter** (voice of the *Late Show with David Letterman*) and **Faith Daniels** (nationally recognized journalist, talk show host, and *debra of America's* President Emeritus). Special guests include former world #1 tennis player, **Mats Wilander**, the Spirit Award winner, Robbie Twible, and **EB Awareness Award** winner, The Friedel Family. The event will recognize the fundraising achievements of the *debra of America* Local Events; Butterfly Wishes For Ellie, Jogging For Jonah, The Rafi's Run Committee, and “What Were We Talking About?” Productions. Proceeds benefit **debra of America**, the only national nonprofit dedicated to funding research for treatments and a cure, while providing free supportive services and programs for those who suffer from Epidermolysis Bullosa.

Tickets to the benefit range from \$150 to \$2,500, with Individual tickets beginning at \$250 and a Couples ticket at \$475. A ‘Young Ambassador’ ticket (30-and-under) is \$150. A ‘Sponsor **EB** Family to Attend Benefit’ ticket is \$1,500 and a ‘Friend of Butterfly Children’ ticket is \$2,500. The benefit is open to all guests.

Purchase tickets or make a donation by visiting: debra.org/benefit, by email: events@debra.org, or by phone: 212-868-1573.

SPONSORSHIP

The 16th Annual debra of America Benefit's title sponsor is Mölnlycke Health Care. Additional sponsorships provided by; JetBlue (Black Chips Sponsor), Scioderm (Black Chips Sponsor), Shire (Black Chips Sponsor), Theorem Clinical Research (Black Chips Sponsor), Fibrocell Science (Green Chips Sponsor), Capstone Partnership (Red Chips Sponsor), DIRECTV (Red Chips Sponsor), Ei Pharmaceutical Solutionworks (Red Chips Sponsor), Hollister Wound Care (Red Chips Sponsor), McKesson Patient Care Solutions (Red Chips Sponsor), Orsini (Red Chips Sponsor), Rosen, Livingston & Cholst LLP (Red Chips Sponsor), Uber (Transportation Sponsor), Urban Agenda NYC (Media Sponsor), Women In Science at Columbia University (University Sponsor).

ABOUT EPIDERMOLYSIS BULLOSA (EB)

Epidermolysis Bullosa (**EB**) is a rare, genetic, connective tissue disorder. There are many genetic and symptomatic variations of **EB**, but all share the prominent symptom of extremely fragile skin that blisters and tears from minor friction or trauma. Internal organs and bodily systems can also be seriously affected by the disease. **EB** is always painful, is often pervasive and debilitating, and is in some cases lethal before the age of 30. **EB** affects 1 out of every 20,000 live births and those born with it are often called “Butterfly Children” because, as the analogy goes, their skin is as fragile as the wings of a butterfly. There is no treatment or cure. Daily wound care, pain management, and protective bandaging are the only options available. Learn more at: debra.org/whatiseb

ABOUT DEBRA OF AMERICA

The Dystrophic Epidermolysis Bullosa Research Association of America was founded in 1980 and is the only national nonprofit dedicated to funding research for treatments and a cure, while providing supportive services and programs for those who suffer from the rare and painful genetic disorder, “Epidermolysis Bullosa (**EB**) – The Worst Disease You've Never Heard Of.™”

Website: debra.org/benefit, Facebook: facebook.com/debraofamerica, Twitter: twitter.com/debraofamerica

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